

Structuring Photovoice for Community Impact: A Protocol for Research With Women With Physical Disability

Macdonald, Diane; Dew, Angela; Boydell, Katherine M.

Veröffentlichungsversion / Published Version
Zeitschriftenartikel / journal article

Empfohlene Zitierung / Suggested Citation:

Macdonald, D., Dew, A., & Boydell, K. M. (2020). Structuring Photovoice for Community Impact: A Protocol for Research With Women With Physical Disability. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 21(2), 1-17. <https://doi.org/10.17169/fqs-21.2.3420>

Nutzungsbedingungen:

Dieser Text wird unter einer CC BY Lizenz (Namensnennung) zur Verfügung gestellt. Nähere Auskünfte zu den CC-Lizenzen finden Sie hier:
<https://creativecommons.org/licenses/by/4.0/deed.de>

Terms of use:

This document is made available under a CC BY Licence (Attribution). For more Information see:
<https://creativecommons.org/licenses/by/4.0>

Structuring Photovoice for Community Impact: A Protocol for Research With Women With Physical Disability

Diane Macdonald, Angela Dew & Katherine M. Boydell

Key words:

photovoice;
disability; arts-
based knowledge
translation;
participatory
research;
integrated
knowledge
translation;
protocol

Abstract: Women with disability face participation barriers based on long-held misconceptions around their identity that adversely affect their health, income levels, and access to education and employment. It has been noted that photographs produced through photovoice methodology can help dismantle attitudinal and environmental barriers that people with disability continue to confront, but this method is rarely assessed for impact. In this protocol paper, we merge principles of feminist theory, photovoice methodology and integrated knowledge translation to generate 1. exhibition-quality participant-created photography on identity, 2. discussion around and insight into inclusion for women with disability and 3. a public exhibition to understand any impact these photographs may have on audiences and discriminatory barriers. Photographs, text, discussions and audience feedback are to be interrogated through thematic and narrative analysis. By aiming our arts-based research findings for a public audience, we hope to advance understanding of female identity and inclusion.

Table of Contents

- [1. Introduction](#)
- [2. Background](#)
 - [2.1 Context](#)
 - [2.2 Overview](#)
- [3. Methods and Design](#)
 - [3.1 Research aims and objectives](#)
 - [3.1.1 Knowledge creation: Exploring identity through arts-based knowledge translation to address stigma and discrimination](#)
 - [3.1.2 Assessing and measuring impact](#)
 - [3.2 Co-researchers and setting](#)
 - [3.2.1 Recruitment method](#)
 - [3.2.2 Inclusion and exclusion criteria](#)
 - [3.2.3 Two settings, knowledge generation and knowledge dissemination/generation](#)
 - [3.3 Stage one: Data generation](#)
 - [3.4 Stage two: Data dissemination, audience feedback for impact](#)
 - [3.5 Data analysis](#)
 - [3.6 Ethical and safety issues](#)
- [4. Discussion](#)
- [Acknowledgements](#)
- [References](#)
- [Authors](#)
- [Citation](#)

1. Introduction

Protocol papers differ from traditional research reports as they detail procedures for ongoing or proposed studies and act as a guide through the enquiry process for future researchers (JACOB & FURGERSON, 2012). In this protocol paper, we describe a methodological innovation to an arts-based research method, photovoice, that uses principles of integrated knowledge translation (iKT) to determine research impact at the community level. Outreach and engagement through the arts can be viewed as a pathway to impact: it can provide opportunities to use research to cause positive social change. It is within this context that we began our research project, using photography as a tool to collect, generate and disseminate research data around female disability identity to promote inclusion, in February 2018, to be completed in October 2021. [1]

In this article, we present a brief overview of photovoice within a disability context (Section 2). Following this, we describe our research design, how to create and disseminate arts-based research for audience impact, and we discuss ethical issues associated with our photovoice project (Section 3). Lastly, we reflect upon the implications that a feminist framework may have on the photovoice process and summarise how arts-based research can help challenge discriminatory barriers (Section 4). We hope by describing this novel approach to photovoice, readers can use and implement aspects of our protocol to increase research impact, particularly when working in the field of female disability. [2]

2. Background

From its inception in Caroline WANG and Mary Ann BURRIS's (1997) study with rural Chinese women, photovoice methodology has been used in a diverse range of health and public health initiatives, including within disability research (CATALANI & MINKLER, 2010; DASSAH, ALDERSEY & NORMAN, 2017; LAL, JARUS & SUTO, 2012). Photovoice is a participatory arts-based research method where members of the team are considered to be co-researchers, to be regarded as collaborators or leaders in the study, rather than subjects (BERGOLD & THOMAS, 2012). They are often from marginalised or vulnerable communities and, for the study, are asked to photograph and discuss aspects of their lives in relation to a central mandate that is usually specified by the research team. Through personal lived experience, co-researchers are viewed as experts of embodied, experiential knowledge. Their contribution is invaluable as they reflect on their lives and communities through photography, and offer guidance throughout the project (KOLB, 2008). [3]

For example, Caroline WANG and Mary Ann BURRIS (1997) sought to gain a better understanding of issues women confronted in rural China by asking them to photograph their everyday lives. These photographs were printed and became catalysts for group discussions that eventually led to change in the form of easier access to fresh water. Following the success of the initial project and its documentation as a research method, photovoice has evolved through the years and has been used in a wide variety of research initiatives, as summarised on the

helpful photovoice.org website, as well as in many feminist studies (MCINTYRE, 2003; MOLESTANE et al., 2009; PÉREZ, GUERRERO, & MORA, 2016; ROBINSON-KEILIG, HAMILL, GWIN-VINSANT & DASHNER, 2014). The process generates a rich output of creative resources including:

- data for analysis, both qualitative and quantitative;
- prompts for individual interviews;
- aids for group discussions;
- artwork (in multiple forms) that can reach and influence a broad range of people. [4]

Besides being a valuable research tool, photovoice has noted benefits for co-researchers: individuals can feel empowered by the process and sense an improvement in well-being, they can develop deeper awareness and reflection of the meaning of lived experience and marginalised groups have a platform to express their views and voice (BRIGHAM, BAILLIE-ABIDI & CALATAYUD, 2018; ROSS, 2017). In addition, co-researchers' voices through this method can have real world impact: art-based knowledge translation is a pathway to reach and influence decision-makers in the community in ways traditional research papers are not able (FRASER & AL SAYAH, 2011). However, this rarely happens. Angela DEW and Katherine BOYDELL (2017) noted that, within disability research, less than 15% of research ever makes it into practice. Accordingly, in our protocol paper we describe an approach to photovoice that includes outcomes designed to reach and influence decision-makers in the community, outside of the research and disability settings. [5]

2.1 Context

It is estimated that worldwide one billion people live with disability, over 15% of the world's population (WHO, 2011). Impairment carries with it preconceived ideas of identity that result in disabling, discriminatory practices, which, in turn, have a negative effect on access to education and employment, community participation, poverty levels and health status for the majority of people labelled as disabled (WORLD BANK, 2013). In addition, any woman or girl with disability will experience even greater rates of discrimination attributable to the combination of her gender and disability (FROHMADER, 2010). These outcomes are not caused by impairment, but by environmental barriers and attitudes that result in disability (WHO, 2011). Intertwined within barriers and attitudes is a perceived reductive identity that devalues or differentiates individuals or groups, resulting in stigma and discrimination (MAJOR & O'BRIEN, 2005). [6]

In this article, we recognise that the use of language is meaningful, fluid and evolving, so we use the term "people with disability" to echo the social model of disability as it applies today in Australia (in other countries, "disabled people" may be preferred). Through this lens, disability results not from outdated notions that people with disability are flawed or inferior, to be pitied or regulated, but from a complex interaction of power structures and specific bodies, minds and senses

(ROHRER, 2005). This model aligns with our underlying belief that society should be inclusive of people with diverse backgrounds and needs, and not seek to fix people to adapt to society (PWDA, 2019; THOMAS, 2004). [7]

Complementing this philosophy, feminist theory mirrors many of the social model's underlying principles: femaleness, like disability, does not equate to inferiority, bad luck or powerlessness. WANG and BURRIS (1994) inculcated photovoice with a feminist approach to question understandings of power, representation and voice in the research process. In addition, Rosemarie GARLAND-THOMSON (2002, p.4), a scholar on disability and feminist theory, determined that "disability—like gender—is a concept that pervades all aspects of culture: its structuring institutions, social identities, cultural practices, political positions, historical communities, and the shared human experience of embodiment". Engaging with images and ideas of disability through a feminist lens can contribute to knowledge around how difference has been (and is) interpreted by others and the consequences of those interpretations. [8]

2.2 Overview

As technology advances and changes, research methods are adapted to keep pace. Increased accessibility to digital cameras (including mobile phones) has led to an increase in participatory photographic research like photovoice in disability (COEMANS, RAYMAKERS, VANDENABEELE & HANNES, 2017; LAL et al., 2012). Photovoice adds to a growing body of visual research (the capturing, processing and expressing knowledge in pictorial, graphic or photographic form) and has been found to be a valuable tool for research (PAUWELS, 2010; SZTO, FURMAN & LANGER, 2005). Photographs and images are a medium to communicate ideas, expressions and emotions in ways that other data cannot (MILLER, 2015). Moreover, visual research can have a dual role as both art and data that can reach broader and unexpected groups through different media and can be considered a pathway for social change and advocacy for communities (BOYDELL, HODGINS, GLADSTONE & STASIULIS, 2017; MITCHELL, 2011). [9]

Although the photovoice method may be growing in practice, there are a limited amount of published photovoice research projects where people with disability are the photographers/co-researchers (MACDONALD, DEW & BOYDELL, 2019). From these disability studies, most researchers concluded that the photovoice process delivered meaningful, descriptive data that were deep and evocative, as well as appropriate for disability research. In addition, many researchers disseminated their findings to a broader audience through exhibitions, presentations and other media, but rarely outside the disability or research communities. Moreover, most researchers from these studies did not describe or measure research impact at the community level, forgoing an opportunity to monitor and assess real change. Importantly, DODD, JONES, JOLLY and SANDELL (2010) acknowledged that widespread and deeply ingrained narrow perceptions of disability identity continue to persist, leading to stigmatisation and discrimination; however, they found that broader social change is possible through exhibitions co-produced with people with disability. [10]

3. Methods and Design

3.1 Research aims and objectives

Our study is divided into two stages: knowledge generation with co-researchers/photographers and later, knowledge dissemination and assessment for impact. In the first stage, we investigated how participatory photographic research can be used as a tool to better understand the experience of disability, especially for women with disability, to challenge attitudinal barriers that lead to stigma, discrimination and exclusion. In the second stage, we will seek to provide evidence of engagement, relevance and significance of photographic research results on audiences outside the research or disability setting. Our research aims to harness the power of visual research to represent marginalised voices, produce data that is accessible and understandable, create opportunities to reach new audiences and provide a rich resource for future research endeavours. As with any creative project, a degree of flexibility and adaptability is needed to accommodate divergent ideas, thoughts and developing pathways that may emerge in the process. [11]

3.1.1 Knowledge creation: Exploring identity through arts-based knowledge translation to address stigma and discrimination

The goal in the first stage was to create a participatory arts-based exhibition-quality body of work that promotes and seeks meaning from marginalised voices, adding fresh perspectives of disability research through photographic enquiry. Photovoice methodology was employed to gain critical understanding of identity and inclusion through the eyes of women identifying as having physical and/or sensory disability and a strong interest in photography. Co-researchers were asked to photograph aspects of their identity from a feminist perspective to produce a sophisticated and nuanced portrait of female disability that could also contribute to feminism's intersectionality (GARLAND-THOMSON, 2002). We believe that the photovoice process is aptly structured to provide our co-researchers with a safe environment to learn more about their female identity and inclusion/exclusion through repeated self-reflection, discussion and visual stimuli on topics central to feminism: power, representation and voice (WANG & BURRIS, 1994). In addition, by exploring these concepts photographically, focusing on lived experience and discussing common occurrences within the group, we hope to promote a greater understanding of the female (disability) experience. [12]

3.1.2 Assessing and measuring impact

In the second stage, we will disseminate an edited group of photographic research results through a public exhibition, see Figure 1. The intended audience, at this stage, is the general public. This could change depending upon co-researcher feedback during discussions. It may become clear that a specific group of stakeholders is an ideal exhibition audience, say, for example, general practitioners or caregivers. Accordingly, to ensure we reach the intended

stakeholders, we will incorporate an iKT strategy, found to be best practice by Angela DEW and Katherine BOYDELL (2017), by answering the following questions:

- What impact do you want your knowledge translation activities to have?
- How will you know if this impact was achieved?
- How will you obtain this information?
- How will the knowledge translation evaluation results be used? [13]

While at the same time it is important to acknowledge:

- clear knowledge translation aims;
- identified stakeholders;
- main research messages;
- audience-specific knowledge translation strategies;
- measurement of impact.

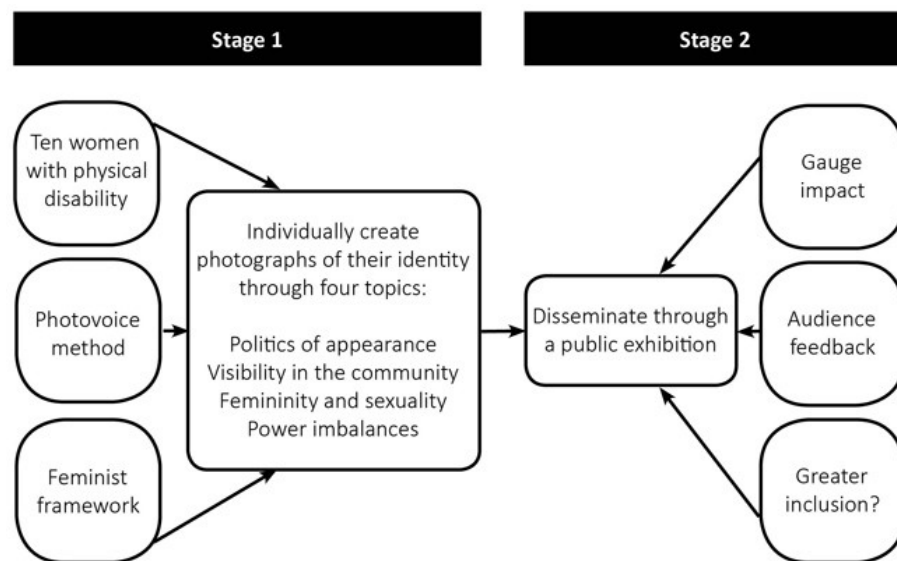


Figure 1: Project plan [14]

3.2 Co-researchers and setting

3.2.1 Recruitment method

After human ethics approval, a website entitled ["Through my eyes"—a research project on disability and identity](#) was created three months before the start of the study, outlining the project requirements and setting, serving as a link that could be shared via e-mail and social media. This platform may have precluded some women (those without internet or social media access); however, given the digital nature of the project, it is unlikely they would have met the inclusion criteria below. From the website, potential co-researchers were able to click on a portal

to register their interest by answering a few questions related to the inclusion criteria in the project. Applications were open for one month prior to the start of the study. The first ten women who met the inclusion criteria were accepted into the program, selected by their registration responses and ability to commit and attend. [15]

3.2.2 Inclusion and exclusion criteria

To take part in the project, we asked potential co-researchers to review the following inclusion criteria to ensure that they:

- identify as a woman with a lifelong physical and/or sensory disability (i.e. not acquired);
- have a strong interest in photography or the arts;
- consent and desire to be publicly identified as artists and authors of the work;
- are able to take photographs with a digital single lens reflex (SLR) camera or work closely and instruct someone else to do so on her behalf—the work must remain as the artist's own;
- are able to attend five workshops over the three-month period;
- are able to communicate via e-mail with the research team leader;
- will e-mail five to ten high resolution photographs prior to each workshop, addressing the current topic;
- agree to a group consensus for selecting photographs for a public exhibition. [16]

Although it may appear counterintuitive to the visual nature of photography, women with vision impairment were welcomed (although none applied). There is a small community of vision impaired photographers, from blindphotographersguild.org to [Instagram's DonnasFight4Sight](https://www.instagram.com/donnasfight4sight/) that illustrates the different creative forces and perspectives that vision-impaired photographers offer. In addition, mobile applications like [TapTapSee](https://www.taptapsee.com/) are equipped with smart phone technology that can describe in spoken word what appears in front of the phone's lens, thus potentially aiding participation in group meetings and discussions. [17]

For clarity, we stipulated the following impairments as exclusion criteria: Intellectual and cognitive impairment (e.g. intellectual disability, autism, Down syndrome, fragile X syndrome, foetal alcohol spectrum disorder). [18]

3.2.3 Two settings, knowledge generation and knowledge dissemination/generation

Five meetings over three months were held in a large accessible meeting room on Saturdays, allowing women who work full-time to take part. From our review of the literature, three months was an effective length of time to collect meaningful data and keep co-researchers engaged. Each session took place over a two-hour period, except the first and last which was three hours to accommodate

discussions around consent and ethics in the first, final photograph selection in the last. For practical planning background information, we found the photovoice.org website to be a valuable resource for structure, training advice and methodological and ethical concerns. [19]

At the first meeting we provided information on the research aims and outcomes, basic photographic techniques and consent. It was most important at this stage to get full ownership of the aims and outcomes by our co-researchers as well as to probe which photographic topics resonated with and were relevant to them. It was also educative (drawing on current feminist photographic bodies of work for inspiration) and interactive (encouraging group discussion on the role of photography and inclusion). Each session ended with a presentation of contemporary feminist photographers for creative inspiration. Co-researchers had two weeks to photograph for the following session. At each subsequent session, their new work was shared on an overhead screen through PowerPoint to encourage group discussion in a supportive and respectful manner. In the middle sessions (two, three and four), we focused on data generation and group discussion of the work, encouraging and aiding authentic voice. Session four included time for co-researchers to review all photographs to date via printed copies, to recognise the body of work each individual and the group were building, and to give guidance on how a joint exhibition would take shape. In session five co-researchers finalised photo selection with captions for both a personal booklet and public exhibition. [20]

In stage two, the setting will take place at a public exhibition to provide us with an opportunity to gauge impact and to understand any affect viewing photographs taken by co-researchers may have on audiences. Once the shape and form of the exhibition was established at the final session, options to host and fund an exhibition were investigated, linked closely to desired stakeholder audience as indicated by co-researchers. It is also important that co-researchers have the option for control and direction at every stage of this project, including dissemination. At this point, our exhibition target is to reach a public audience through an accessible city library. [21]

3.3 Stage one: Data generation

In their review of the literature of feminist frameworks within photovoice studies, COEMANS et al. (2017) found little evidence of practical implementation of a feminist approach to female photovoice studies. As a result, the authors recommended that any theoretical framework should be made explicit at the start of the study. Accordingly, in stage one of our research, co-researchers were asked to construct representations of their identities through photography using a feminist framework. We employed feminist theory to concentrate the focus of our research by narrowing our investigation of disability identity into topics specific to feminism. Namely, we explored concepts of the politics of appearance, exclusion, visibility, power imbalances, sexuality and reproductive rights, while at the same time investigating some of the diverging realities of institutional, environmental and social structures specific to disability (GARLAND-THOMSON, 2002).

Moreover, as researchers we identify as non-disabled (for now) feminists, we believe this approach can deepen our understanding of the research process into disability, as well as enable a reflective insight into female identity and inclusion. In addition, as authors and designers of this research, our different perspectives, strengths and limitations add depth to this mix: 1. as a professional photographer, 2. as expert in disability and knowledge translation and 3. as an arts-based knowledge translation and mental health researcher. [22]

Identity, itself, is a fluid and complex subject that can take on a vast array of forms, including concepts of sexuality, occupation, citizenship as well as situational, internal, cultural and external roles and more. A key to what creates barriers for women with disability is a reductive view of their identity, namely that they have only one—that of a person with impairment. To give structure through a feminist lens to aid the photographic process, we suggested four topics for co-researchers to consider:

1. politics of appearance, difference and the body;
2. exclusion, inclusion and visibility in the community;
3. femininity, sexuality, relationships and reproductive rights;
4. equality, power and power imbalances. [23]

To facilitate generation of photographs of identity, we produced a framework that marries roles, topics and personal creativity to act as a guide to inspire fresh, bold creative photography with a sound theoretical background, see Figure 2. Textual captions, titles or stories were encouraged to offer greater insight. As a professional photographer, first author Diane was available to assist as needed, either physically or technically.

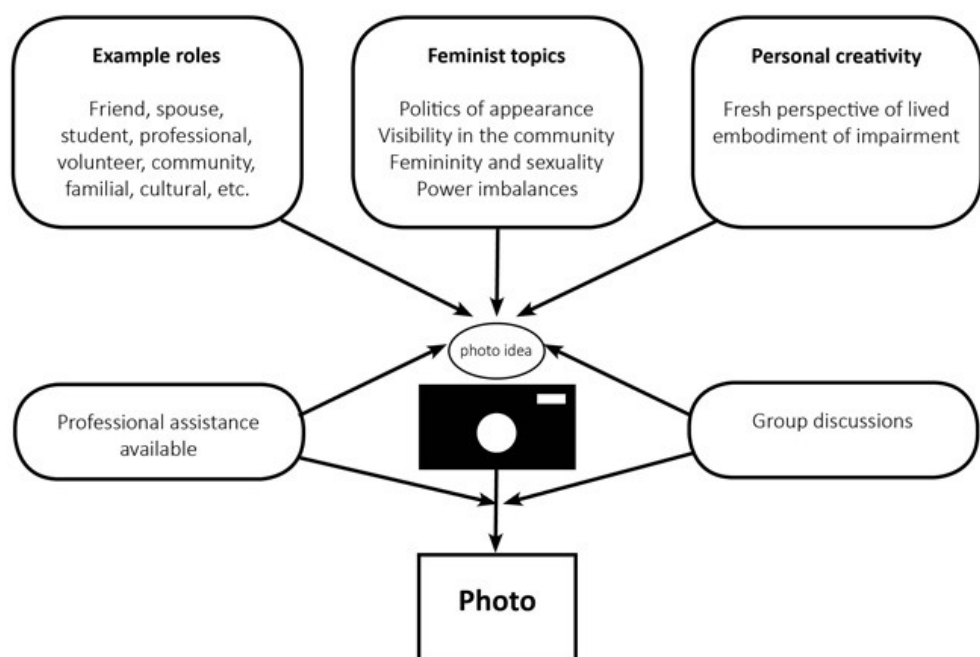


Figure 2: Data generation model [24]

In addition to photographs, other data generated in this period included qualitative semi-structured video interviews with co-researchers, audio recordings of group discussions and creation of personal booklets. When we conduct our analysis over the coming months, these sources will enrich our ability to explore and investigate the complex nature of female disability identity. [25]

3.4 Stage two: Data dissemination, audience feedback for impact

Taking into consideration how rarely photovoice reaches beyond the disability or research communities, our project was structured to produce a public exhibition not only to share research findings but also to assess impact. For the public, the aesthetic and participatory experience of an art exhibition can reawaken the senses, enabling consciousness of what has been taken for granted or accepted previously, potentially leading to social change (GREENE, 1995; SANDELL & NIGHTINGALE, 2012). Photographs will be displayed at a city library. Impact will be assessed through audience feedback cards and convenience sampling interviews. Our feedback card is based on DODD et al.'s investigation into disability in the gallery setting, who found the following question to be most effective at prompting visitors to think directly about issues around disability and representation: *How does this display change the way you think about disability?* We altered the question slightly, to remove the assumption that change occurred: *Does the display "Through my eyes" change the way you think about disability? If so, how?*

The feedback card is titled "Talking about... DISABILITY, PHOTOGRAPHY and EXCHANGING KNOWLEDGE". It features a large, empty thought bubble in the center. To the left of the bubble, the text reads: "Does the display 'Through my eyes' change the way you think about disability? If so, how?". Below this, it says: "Please write or draw your response in the bubble." To the right of the bubble, there is a small icon of a pencil. At the bottom right, it says: "Please complete and place in box or on board provided."

Figure 3: Feedback card, based on DODD et al (2010, p.96) [26]

3.5 Data analysis

Generation of research data will produce multiple sets of data—photographs, textual descriptions, booklets, narratives from individual and group interviews and audience feedback cards. These data sets will enable us to develop a rich interrogation of how women with disability represent female identity and their experiences of inclusion and connection through photography. They represent data that can be seen as fragments and as a whole, creating tension and complexity that will hopefully add to and solidify analytical findings. Moreover, the data, produced in exhibition form in stage two, offers an opportunity for us to analyse how audiences will engage and interpret their experience of the exhibition. [27]

We will combine two best practice qualitative analytical techniques, thematic analysis and narrative analysis, used in tandem, to interrogate research data through completely different methods. We will employ thematic analysis to fracture data to find commonalities and repeated patterns of meaning by actively pursuing and developing themes through rigorous interrogation (BRAUN & CLARKE, 2013). In contrast, narrative analysis, by preserving stories in their entirety as the core of investigation, will enable us to interrogate personal, social and cultural experiences and, hopefully, uncover additional insights (RIESSMAN, 1993). By merging these two techniques, we can potentially uncover hidden tensions and strengthen analytical findings. In addition, our analysis will benefit from guidance and feedback from co-researchers, depending upon individual response to a longer-term involvement in the project. [28]

3.6 Ethical and safety issues

There are noted benefits for those who participate in photovoice projects. In "The Photovoice Manual" (BLACKMAN & FAIREY, n.d.), several are identified, such as —thinking skills: self-awareness, social awareness, goal-setting, problem solving and decision-making; social skills: appreciating and validating others, building positive relationships; negotiation and decision-making skills; and photographic/artistic skills that can lead to self-development, self-esteem and in some cases a new career. In addition, for people with disability, the role of the arts and art generation continue to be effective in helping increase social inclusion and personal well-being (THOMPSON, FURMAN, SHAFI & ENTERLINE, 2012). [29]

There are also risks associated with conducting photovoice research and especially within disability photovoice studies that can have direct or indirect negative consequences. These can include trauma around: uncovering buried emotions unconsciously embedded within photographic process and the photographs themselves, informed consent, power imbalances, both historical and within the research setting; and, exploitation, reinforcement of subjugation and stereotyping (BLACKMAN & FAIREY, n.d.; WANG & REDWOOD-JONES, 2001). Considering these risks, ethics committees may be reticent in granting ethics approval for using visual images in disability research, as noted in BOXALL

and RALPH (2009). This reticence may, in turn, lead to a lag or gap in academic research, possibly losing pace with journalists, disability organisations and members of the public (ibid.). Moreover, arts-based research within disability, while increasing in use, continues to remain underexplored (BOYDELL, GLADSTONE, VOLPE, ALLEMANG & STASIULIS, 2012). For additional insight into mitigating ethical challenges and risks associated with arts-based health research, Katherine BOYDELL has identified several strategies which may prove useful (BOYDELL, SOLIMINE & JACKSON, 2017; BOYDELL et al. (2012); COX & BOYDELL, 2016; LENETTE et al., 2018). [30]

To minimise any possible harm as well as to address trauma should it occur, each meeting ended with a PowerPoint slide that documented useful mental health organisation's contact details (in Australia, for example, [Black Dog Institute](#), [Beyond Blue](#) and [Lifeline](#)). In addition, the chief investigator's phone number and e-mail address were included as a point of contact, should any co-researcher have any concerns or questions. Our aim was to create a safe environment to foster inclusion, and at each meeting we made it clear that each and every voice was welcomed. [31]

In addition, in our research project, anonymity of our co-researchers (photographers) was considered to be counterintuitive to the philosophical underpinnings and aims of the project. In a recent study in the UK it was found that people who identify as disabled are significantly excluded from the creative sector (BROOK, O'BRIEN & TAYLOR, 2018). In the U.S., Guerrilla Girls, a group of anonymous feminist activist artists, updated their 1989 well-known project "weenie counts" with new statistics: only 4% of artists in the modern art section of the Metropolitan Museum of Art were women while 76% of the nudes were female (ANONYMOUS, 2012). It was essential that co-researchers were recognised and promoted in this project and agreed to being identifiable to help address inequities in the art world. Furthermore, we took into consideration that photography as a medium has misused women in the past (KELLY, 2003). Therefore, it was vital that co-researchers retained control over their photographic practice, maintained copyright and ownership and had space for creative development and presentation (COX & BOYDELL, 2016). [32]

To help co-researchers feel comfortable with our research process, clearly defined structural guidelines in *plain English* language were provided to enable understanding of 1. the outline of the project; 2. how photos will be used; 3. the length of the project and of individual workshop sessions; 4. who will be working with them; 5. where the workshops will take place, 6. the final outputs and endpoint and 7. their role as recognised artists, co-researchers and authors. Further involvement as co-authors of proposed papers, presenters and analysts of data were discussed in person, at meetings four and five. It was important to outline clear parameters of the project (beginning and end dates), yet at the same time leave room for further exploration by individuals, if desired. In addition, this information was printed and made available on the project's [website](#), to ensure uniformity and enable accessibility. [33]

Reflected in our philosophic approach to this study was that visual research should be done voluntarily, be worthwhile and respectful; and be undertaken in an informed and independent manner, free from conflict of interest as articulated by Gillian ROSE (2012). Our decision-making process of photograph selection included her ethical and moral framework around consent, copyright and anonymity, as well as reflected both the individual photographer's and the group's voice (p.359). Their voice and vision were and are critically essential to the success of our project and were and will be supported throughout the study, in a non-patronising manner. We were aware, as well, that a tension, between producing a coherent body of group work for a public audience and potentially diverging individual artist's visions, was a possibility. Through group discussions and open lines of communication, we hoped any issues could be resolved. [34]

4. Discussion

Through developing a collaborative body of art where women with disability were the artists, we hope to address a lack of representation in the art world; aim to increase the artists' sense of identity, connection and inclusion; strengthen the voice and role of a marginalised group; measure photovoice's impact in a public arena, beyond the research or disability setting; create a basis for future research endeavours and present a unique view of female identity that can be exhibited on a national and international level. Visual research, produced inclusively with people with lived experience of disability can be seen as a credible pathway and opportunity for marginalised voices to be seen and heard, potentially adding fresh perspectives of disability which can lead to social change (GARLAND-THOMSON, 2010). [35]

The aim of our research, as stated at the beginning of this article, is to advance understanding of female identity and inclusion to address barriers that keep women with disability apart. Through the act of photographing, through self-reflection and discussion, and more broadly, through empathetic engagement with photographs and accompanying stories, we hope to frame and promote messages of inclusion, equality and visibility: of claiming space for women with disability in the community. Furthermore, we borrow words from Kimberlé CRENSHAW, a leading scholar on black feminist legal theory, as it applies to our research aims: it is "our intention to hold these women up, to sit with them, to bear witness to them, to bring them into the light" (2016, at 15:45). [36]

We acknowledge that imposing a feminist framework to shape and mould photographic enquiry may have hindered co-researchers' voice and creativity. Yet at the same time, structure that included a solid theoretical basis was needed to lay the foundation for a cohesive group exhibition. While this is an ambitious project, to create exhibition-quality photographs on identity with a group of strangers in three months, it also creates an opportunity to explore why art by people with disability is rarely seen in public. In addition, our project can be seen as a pathway to increased access and participation in the art world for female photographers with impairment, leading to a greater diversity of voice in the art world. Moreover, through our co-produced research, we aim to address

discriminatory barriers through inclusive, arts-based enquiry and offer a platform through which audiences can reflect upon their own considerations of disability. [37]

Acknowledgements

The first author, Diane MACDONALD, is a recipient of an Australian Government Research Training Program Scholarship.

References

- Anonymous (2012). Do women still have to be naked to get into the Met. Museum?, <https://www.guerrillagirls.com/naked-through-the-ages/> [Accessed: April 12, 2018].
- Bergold, Jarg & Stefan Thomas (2012). Participatory research methods: A methodological approach in motion. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 13(1), Art. 30, <http://dx.doi.org/10.17169/fqs-13.1.1801> [Accessed: November 11, 2019].
- Blackman, Anna & Fairey, Tiffany (n.d.). *The photovoice manual*, member access only, <https://photovoice.org/> [Accessed: May 1, 2018].
- Boxall, Kathy & Ralph, Sue (2009). Research ethics and the use of visual images in research with people with intellectual disability. *Journal of Intellectual & Developmental Disability*, 34(1), 45-54.
- Boydell, Katherine M.; Solimine, Carmela & Jackson, Siona (2017). Performative dance and the ethics of embodying difficult experiences. In Deborah Warr, Marilys Guillemain, Susan Cox & Jenny Waycott (Eds.), *Ethics and visual research methods: Theory, methodology and practice* (pp.201-210). New York, NY: Palgrave Macmillan.
- Boydell, Katherine M.; Hodgins, Michael; Gladstone, Brenda & Stasiulis, Elaine (2017). Ineffable knowledge: Tensions (and solutions) in art-based research representation and dissemination. *Journal of Applied Arts & Health*, 8(2), 193-207.
- Boydell, Katherine M.; Gladstone, Brenda; Volpe, Tiziana; Allemang, Brooke & Stasiulis, Elaine (2012). The production and dissemination of knowledge: A scoping review of arts-based health research. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 13(1), Art. 32, <http://dx.doi.org/10.17169/fqs-13.1.1711> [Accessed: March 22, 2018].
- Boydell, Katherine M.; Volpe, Tiziana; Cox, Susan; Katz, Arlene; Dow, R.; Brunger, F.; Parsons, J.; Belliveau, G.; Gladstone, B.M.; Zlotnik Shaul, R.; Cook, S.; Kamensek, O.; Lafreniere, D. & Wong, L. (2012). Ethical challenges in arts-based health research. *International Journal of the Creative Arts in Interprofessional Practice*, 11, 1-18.
- Braun, Virginia & Clarke, Victoria (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage.
- Brigham, Susan; Baillie-Abidi, Catherine & Calatayud, Sylvia (2018). Migrant women learning & teaching through participatory photography. *The Canadian Journal for the Study of Adult Education*, 30(2), <https://cjsae.library.dal.ca/index.php/cjsae/article/view/5433> [Accessed: June 11, 2019].
- Brook, Orian; O'Brien, David & Taylor, Mark (2018). *Panic! It's an arts emergency: Social class, taste and inequalities in the creative industries*. London: Arts and Humanities Research Council, <https://createlondon.org/event/panic-paper/> [Accessed: June 25, 2018].
- Catalani, Caricia & Minkler, Meredith (2010). Photovoice: A review of the literature in health and public health. *Health Education & Behavior*, 37(3), 424-451.
- Coemans, Sara; Raymakers, Anne-Leen; Vandenabeele, Joke & Hannes, Karin (2017). Evaluating the extent to which social researchers apply feminist and empowerment frameworks in photovoice studies with female participants: A literature review. *Qualitative Social Work: Research and Practice*, 18(1), 37-59.
- Cox, Susan & Boydell, Katherine (2016). Ethical issues in arts-based health research. In Stephen Clift & Paul Camic (Eds.), *Creative arts, health, and wellbeing: International perspectives on practice, policy, and research* (pp.78-92), Oxford: Oxford University Press.
- Crenshaw, Kimberlé (2016). The urgency of intersectionality. *Video recording*, TED Women2016 Talks, https://www.ted.com/talks/kimberle_crenshaw_the_urgency_of_intersectionality/transcript?language=en#t-1012684 [Accessed: September 18, 2019].

- Dassah, Ebenezer; Aldersey, Heather & Norman, Kathleen (2017). Photovoice and persons with physical disabilities: A scoping review of the literature. *Qualitative Health Research*, 27(9), 1412-1422.
- Dew, Angela & Boydell, Katherine (2017). Knowledge translation: Bridging the disability research-to-practice gap. *Research and Practice in Intellectual and Developmental Disabilities*, 4(2), 142-157.
- Dodd, Jocelyn; Jones, Ceri; Jolly, Debbie & Sandell, Richard (2010). Disability reframed: Challenging visitor perceptions in the museum. In Richard Sandell, Jocelyn Dodd & Rosemarie Garland-Thomson (Eds.), *Re-presenting disability* (pp.92-111). Abingdon: Routledge.
- Fraser, Kimberly & al Sayah, Fatima (2011). Arts-based methods in health research: A systematic review of the literature. *Arts & Health*, 3(2), 110-145.
- Frohman, Caroline (2010). *Gendering the National Disability Care and Support Scheme*. Policy submission, <http://wwda.org.au/wp-content/uploads/2013/12/WWDASubPCInquiry2010.pdf> [Accessed: January 25, 2018].
- Garland-Thomson, Rosemarie (2002). Integrating disability, transforming feminist theory. *NWSA Journal*, 14(3), 1-32.
- Garland-Thomson, Rosemarie (2010). Picturing people with disabilities. In Richard Sandell, Jocelyn Dodd & Rosemarie Garland-Thomson (Eds.), *Re-presenting disability* (pp.23-40). Abingdon: Routledge.
- Greene, Maxine (1995). *Releasing the imagination: Essays on education, the arts, and social change*. San Francisco, CA: Jossey-Bass.
- Jacob, Stacy & Furgerson, S. Paige (2012). Writing interview protocols and conducting interviews: Tips for students new to the field of qualitative research. *Qualitative Report*, 17, Art. 6, 1-10, <https://nsuworks.nova.edu/tqr/vol17/iss42/3> [Accessed: March 30, 2020].
- Kelly, Angela (2003). Personal is political. In Liz Wells (Ed.), *The photography reader* (pp.410-416). Abingdon: Routledge.
- Kolb, Bettina (2008). Involving, sharing, analysing—Potential of the participatory photo interview. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 9(3), Art. 12, <http://dx.doi.org/10.17169/fqs-9.3.1155> [Accessed: November 11, 2019].
- Lal, Shalini; Jarus, Tal & Suto, Melinda (2012). A scoping review of the photovoice method: Implications for occupational therapy research. *Canadian Journal of Occupational Therapy*, 79(3), 181-190.
- Lenette, Caroline; Botfield, Jessica; Boydell, Katherine M.; Haire, Bridget; Newman, Christy & Zwi, Anthony (2018). Beyond compliance checking: A situated approach to visual research ethics. *Journal of Bioethical Inquiry*, 15(2), 293-303.
- Macdonald, Diane; Dew, Angela & Boydell, Katherine (2019). Representation and knowledge exchange: A scoping review of photovoice and disability. *Journal of Applied Arts & Health*, 10(2), 185-201.
- Major, Brenda & O'Brien, Laurie (2005). The social psychology of stigma. *Annual Review of Psychology*, 56, 393-421.
- Mcintyre, Alice (2003). Through the eyes of women: Photovoice and participatory research as tools for reimagining place. *Gender, Place & Culture*, 10(1), 47-66.
- Miller, Kyle Elizabeth (2015). Dear critics: Addressing concerns and justifying the benefits of photography as a research method. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 16(3), Art. 27, <http://dx.doi.org/10.17169/fqs-16.3.2434> [Accessed: November 11, 2019].
- Mitchell, Claudia (2011). *Doing visual research*. Los Angeles, CA: Sage.
- Moletsane, Relebohile; Mitchell, Claudia; de Lange, Naydene; Stuart, Jean; Buthelezi, Thabisile & Taylor, Myra (2009). What can a woman do with a camera? Turning the female gaze on poverty and HIV and AIDS in rural South Africa. *International Journal of Qualitative Studies in Education*, 22(3), 315-331.
- Pauwels, Luc (2010). Visual sociology reframed: An analytical synthesis and discussion of visual methods in social and cultural research. *Sociological Methods Research*, 38, 545-581.
- Pérez, Michelle; Guerrero, Margarita Ruiz & Mora, Elaine (2016). Black feminist photovoice: Fostering critical awareness of diverse families and communities in early childhood teacher education. *Journal of Early Childhood Teacher Education*, 37(1), 41-60.

- PWDA (2019). *People with disability Australia*, <https://pwd.org.au/resources/disability-info/social-model-of-disability/> [Accessed: May 9, 2019].
- Riessman, Catherine Kohler (1993). *Narrative analysis*. Newbury Park, CA: Sage.
- Robinson-Keilig, Rachel; Hamill, Cynthia; Gwin-Vinsant, Annalisa & Dashner, Matthew (2014). Feminist pedagogy in action: Photovoice as an experiential class project. *Psychology of Women Quarterly*, 38(2), 292-297.
- Rohrer, Judy (2005). Toward a full-inclusion feminism: A feminist deployment of disability analysis. *Feminist Studies*, 31(1), 34-63.
- Rose, Gillian (2012). *Visual methodologies an introduction to researching with visual materials* (4th ed.). London: Sage.
- Ross, Karen (2017). Making empowering choices: How methodology matters for empowering research participants. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 18(3), Art. 12, <http://dx.doi.org/10.17169/fqs-18.3.2791> [Accessed: November 11, 2019].
- Sandell, Richard & Nightingale, Eithne (Eds.) (2012). *Museums, equality and social justice*. Abingdon: Routledge.
- Szto, Peter; Furman, Rich & Langer, Carol (2005). Poetry and photography: An exploration into expressive/creative qualitative research. *Qualitative Social Work*, 4(2), 135-156.
- Thomas, Carol (2004). How is disability understood? An examination of sociological approaches. *Disability & Society*, 19(6), 569-583.
- Thompson, Riki; Furman, Rich; Shafi, Noel & Enterline, Michelle (2012). Poetry, masculinities, and disability. *Journal of Poetry Therapy*, 25(2), 105-114.
- Wang, Caroline & Burris, Mary Ann (1994). Empowerment through photo novella: Portraits of participation. *Health Education Quarterly*, 21(2), 171-186.
- Wang, Caroline & Burris, Mary Ann (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior*, 24(3), 369-387.
- Wang, Caroline & Redwood-Jones, Yanique (2001). Photovoice ethics: Perspectives from flint photovoice. *Health Education & Behavior*, 28(5), 560-572.
- WHO (2011). *World report on disability*, https://www.unicef.org/protection/World_report_on_disability_eng.pdf [Accessed: February 8, 2018].
- World Bank (2013). *Inclusion matters: The foundation for shared prosperity* (adv. ed.), http://siteresources.worldbank.org/EXTSOCIALDEVELOPMENT/Resources/244362-1265299949041/6766328-1329943729735/8460924-1381272444276/InclusionMatters_AdvanceEdition.pdf [Accessed: February 8, 2018].

Authors

Diane MACDONALD, BSc MBA MDP is a doctoral candidate at the School of Psychiatry UNSW Sydney and Black Dog Institute at UNSW Sydney. Her research area focuses on the intersection of photography, gender and social justice. Previously, Diane was the managing editor of the *Australian Journal of Human Rights*, the photo editor of the *Human Rights Defender* and the centre manager for the Australian Human Rights Centre based at UNSW Law. She holds a master of documentary photography, a master of business administration and has been a professional photographer for over 30 years.

Contact:

Diane Macdonald
School of Psychiatry and Black Dog Institute
UNSW Sydney
Hospital Road, Randwick NSW 2031, Australia
Tel.: +612 9382-4530
E-mail: diane.macdonald@unsw.edu.au
URL: <https://www.blackdoginstitute.org.au/>

Angela DEW, PhD is associate professor disability and inclusion at Deakin University, Melbourne where she is engaged in research and teaching related to people with disability and complex support needs. Angela is a sociologist with 38 years' experience in the Australian disability sector. Her research relates to understanding the specific issues faced by people with cognitive disability and a range of complexities including living in rural and remote locations and coming from an Aboriginal or refugee background. Angela uses qualitative and arts-based methods within an integrated knowledge translation framework to ensure her research results in practical solutions that can be tailored to individuals and local communities.

Contact:

Angela Dew

Deakin University
Burwood Campus
221 Burwood Highway, Burwood Victoria 3125, Australia

E-mail: angela.dew@deakin.edu.au

URL: <https://www.deakin.edu.au/>

Katherine BOYDELL, MHSc, PhD is professor of mental health at the Black Dog Institute and head of Knowledge Translation, Sydney Partnership on Health, Education, Research and Enterprise (SPHERE). She also holds several adjunct positions at leading Canadian institutions: Adjunct senior scientist, Child and Youth Mental Health Research Unit, Hospital for Sick Children, Toronto; adjunct professor, Department of Psychiatry and Dalla Lana School of Public Health, University of Toronto; adjunct professor, Graduate Program in Theatre, York University, Toronto. Her program of research focuses on understanding the impact of using a wide variety of art genres in child and youth mental health research, for both knowledge production and knowledge dissemination.

Contact:

Katherine Boydell

School of Psychiatry and Black Dog Institute
UNSW Sydney
Hospital Road, Prince of Wales Hospital,
Randwick NSW 2031, Australia

Tel.: +612 9382-4530

E-mail: k.boydell@blackdog.org.au

URL: <https://www.blackdoginstitute.org.au/>

Citation

Macdonald, Diane; Dew, Angela & Boydell, Katherine M. (2020). Structuring Photovoice for Community Impact: A Protocol for Research With Women With Physical Disability [37 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 21(2), Art. 16, <http://dx.doi.org/10.17169/fqs-21.2.3420>.